



"In the last few days, even something little sets me off.

I find myself yelling all the time. Then of course I end up feeling guilty. Poor Jim. He doesn't deserve this."

You may be exhausted. When you are rested and fit, you feel good about yourself, you're more tolerant of common irritants, more accepting of annoying behaviors, and you tend to see more options for solving problems. Try to get some rest or a break from the caregiving routine.

"More and more I feel empty inside, like I have no feelings, no pleasure in anything. I also have this fear that one day I am going to explode, and all these feelings are going to come from somewhere deep inside. It is frightening because I am afraid that something dreadful will happen."

When we are running on empty, all emotions are dulled. We are just too tired to feel anything. It does not mean that anger, fear, and sadness are not there. Reach out. Get help. You can feel better. If family help is not available, look for paid services in your community.

"I am so tired of cleaning up behind him and everything else I have to do over and over and over. It's never-ending and I'm past the boiling point."

Decide what's worth doing and what you can give up. Delegate what you can and do only what's necessary. Lower your standards. Get rid of everything you don't use or need. Order brings a sense of control but should not be at the cost of drudgery.

"Last night I actually broke three of my best wine goblets. I just needed to hit or break something. This morning I feel so foolish. I'm also mad at my husband. I know that's unreasonable. Why do I need somebody to blame?"

Sometimes when we feel helpless or at a loss to control a situation, we feel better if we blame someone or something. You have a right to be angry at the situation but remember your husband is not the problem. Blame the disease. Healthy ways to express and work off anger: Go for a walk, bake or cook something that takes time and attention, call a friend, pray, clean a closet or whatever works for you.

"There are things he does that set me off. 'He's doing this to spite me.' I see them coming and yet, I respond the same way every time."

Wait a minute. Count to ten before you respond. This really works. Maybe he needs reassurance, more structure (or less structure) a job or an activity that he can do without the expectation of perfection or standards that he can no longer attain, and appreciation for things he can still do. He also needs affection though it may be hard to be affectionate when you are mad. What are those things that always make you mad? Can these be changed in any way so they are less upsetting to you? The only option may be to change your attitude about these triggers.

"I know that life is not fair but it still makes me so mad! Almost every day, I ask: 'Why us?' 'Why her?' And then there's that awful answer from out of somewhere, 'Why not you?' 'Why not her?'"

Alzheimer's robs so much from the person who has it and from those who love and care for him or her. Keeping journals is one small way of responding: Write down all the good things you want to remember—some may be funny, some painful, some totally new information to other members of the family. In a separate journal write about the problems, losses, challenges, the anger and the triumphs of the caregiving journey. This may help maintain your perspective and sense of control. Families report that these journals become treasures later.

"I am furious at the nursing home but
I am afraid to say anything. If I have to
move dad again, I don't know what I'II do.
Today was the last straw. I walked in to see him and
they had cut off all of his hair. It was as if someone
had decided that this was one way not to have to give
him another haircut. I wanted to cry. He was always
so particular about his hair."

Always speak up when there is a problem or concern about your family member's care. The trick is knowing how. First, wait until you have calmed down, if you are angry. It may help to write down all of the issues to help you focus clearly. Focus only on the current concern, not everything that has been bothering you the whole year. Go to the right person first. If you are upset with the nursing assistant, talk first to him or her. Let her tell her side and LISTEN. You may be unaware of extenuating circumstances. If you are still not satisfied, talk to her supervisor, then the administrator, then the ombudsman—an ideal advocate for your family member. You may even want to start with the ombudsman if you are afraid of rocking the boat in the nursing home.

"I have to do everything myself. My mother has five children—my four brothers don't think Mom has a problem. The only good thing about this disease is that she's not aware of their terrible behavior. Their only concern seems to be whether or not I am spending her money frivolously on her care."

You cannot make your brothers share in your mother's care. You ask and then emotionally let it go when they refuse. You can only learn to make the job as easy for you as possible. For now, get a durable power-of-attorney for health care, and plan for facility care if that becomes necessary. Keep meticulous records of spending for her and show them to your brothers. Try a to-do calendar: taking Mom to the doctor one Tuesday a month, picking her up from the Adult Day Center at 3 p.m. each day. If she lives alone, assign maintenance chores such as cutting grass or picking up groceries. Let each of your brothers choose what he will be responsible for.



Duke Family Support Program and the Joseph and Kathleen Bryan Alzheimer's Disease Research Center This new education/awareness product was developed for NC's Project C.A.R.E. (Caregiver Alternatives to Running on Empty), an Administration on Aging Alzheimer's Demonstration Grant. "Wait a Minute!" is adapted from Duke's popular book, Pressure Points: Alzheimer's and Anger (2000), available for \$8.00 pre-paid from Duke Family Support Program, 3600 DUMC, Durham, NC 27710. (919) 660-7510 • Toll-free in NC ONLY: (800) 672-4213

"I'm trying. Nobody seems to appreciate that. My children and everybody just tell me what I'm doing wrong. Taking care of Amy is a full-time job. Sure I've yelled at her a few times. Last night I shook her really hard. I took her to the toilet and when I went back to check on her she had made a mess everywhere except in the toilet. Like lightning, I lost it. My kids talk psychology, but not one of them wipes butts."

All of us need information or help if we care. It's not always easy even when you know HOW to do a job to bathe the person, how to get her to eat, to use the toilet The experts tell us that giving care is hard because we not only care for the person (like helping with bathing or taking to the toilet) but we care about the person (like loving a wife and hurting when we see what's happening to her). We forget that the first and maybe even the most important job is keeping ME, the caregiver, well so that anger doesn't take over as easily when the going gets rough.

have good ideas. Take mini-vacations even if they are planned, regular "daydream excursions." Laugh. Get real breaks by actually getting away for a while. Think of your body as a machine and make a special effort to take care of it. It's not unlike taking care of your car. How far would you get without gas or water in your car? Eat regular meals for the energy you need. Sleep to repair the wear and tear of the

"You tell me to take care of myself. How do I do that

Go to support groups where others in the same boat

and what good would that do?"

day. Exercise regularly—this is a great way to build strength and work off anger. Finally, learn to accept things that you cannot change. Learn how to triumph, even in small ways, despite what you can't change.

to listen without giving advice or comment. Most people don't know how to just listen. Make a contract, explaining to your friend that you just need someone to listen and understand what you are going through at the moment. One wife called this her "bitching partner"—a woman she could call anytime when she needed to rant and rave and hang up once she calmed down.



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